

Originalartikel

# Living with illness

## *Together and alone facing severe illness in four Scandinavian cancer stories*

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*In this paper, I wish to discuss how people living with severe illness at home depict their lives either in a family setting or alone. Roland Barthes writes in *Comment vivre ensemble* (1977) about individual life lived in a variety of collective situations in different settings, and calls this *idiorrhythmia*. One of the settings Barthes studies is the sanatorium, where the figures of *Autarky* and *Clôture*, implying living together and living alone, are made relevant. I will use the concept of *idiorrhythmia*, to discuss ill people living at home either alone or together with relatives. The discussion is based on four contemporary Scandinavian novels: Lars Gustafsson's *The Death of a Beekeeper* (1978), Ragnar Hovland's *A Winter's Journey* (2001), Gunnhild Corwin's *Ida's Dance* (2005) and Ellisiv Stifoss-Hanssen's *Let me sleep until this is just a dream* (2014). These novels describe young and old adults suffering from cancer, staying at home and the challenges and strategies involved in living together or alone while experiencing severe illness.*

According to the French literary critic, Roland Barthes (1915-1980), novels as a genre are particularly fruitful for exploring the manner in which people live alone or together in different social settings. Barthes uses the concept of “*idiorrhythmia*”, originally used to describe individualized monastic life and meaning “following

one's own devices" (Talbot, 2005). In *Comment vivre ensemble* (1977), Barthes reflects upon how people living on an island, in a monastery or a sanatorium, balance living together with living alone. At the sanatorium, people live together with other sick people and staff preoccupied with taking care of them. But what is it like being a patient at home, alone or together with people who are both family members and caregivers?

How patients live with others is pivotal, not only with regard to health care services but also as part of a social community. As early as 1943, John Ryle (1889–1950), the first professor of social medicine in England, wrote that it was necessary to study "[...] " (Strøm, 1956:11). Ryle argued, that clinical medicine had evolved into a practice strongly characterized by technique and that the human being, both as an individual and as a member of a family and of social groups, had been forgotten. Ryle's observation from 1943 still remains relevant. As healthcare interventions often take place over short periods of time, the patient's family members form an authority that has become steadily more important. For an ill person, the majority of time is not spent at the hospital, but at home; the patient has more interaction with relatives than with health personnel. Thanks to the almost revolutionary developments in medicine over the last century, patients have on the one hand become dependent on clinicians in order to receive accurate and efficient treatment, but on the other hand spend less and less time in contact with healthcare services. The reduced time spent in a health facility as an outpatient or inpatient has increased the importance of other authorities in patients' everyday lives. This applies particularly to relatives such as partners, spouses, parents and siblings, or friends.

I wish to explore how living with illness, together and/or alone, is depicted in four Scandinavian stories about cancer. Lars Gustafsson's *The Death of a Beekeeper* (1978) tells the story of the cancer-stricken main character Lars Lennart Westin's final six months before his death. He is a divorced teacher who has taken early retirement and lives alone while he is ill, but the book also provides flashbacks to his childhood and his marriage. Ragnar Hovland's *A Winter's Journey* (2001) depicts a couple where the man was diagnosed with stomach cancer in his late fifties, while Gunnhild Corwin's *Ida's Dance* (2006) is a documentary account of 18-year-old Ida, who is suffering from leukaemia. The story covers the six months up to Ida's death, shortly after her 18th birthday. In *Let me sleep until this is just a dream*, Ellisiv Stifoss-Hanssen tells the story of Mia, 26 years old and diagnosed with cervical cancer, and her parents, after the break-up of her relationship with her girlfriend Anne-Marie.<sup>1</sup>

The selected texts reveal two sets of care roles, namely the relationships of the relatives of young adults (<30) and of adults (>40).<sup>2</sup> All the protagonists have hospital appointments but live in their own or their parents' home and it is these private places of illness I would like to dwell on. The books are different with respect to genre and degree of authenticity, but they all share a focus on the significance of close relatives as the illness progresses and all give less emphasis to the functions of the hospital and the doctor. The novels demonstrate a variety of strategies and challenges connected to the act of living together when a family member experiences serious illness. Here I wish to draw attention to how former social roles as wife, parents and siblings change due to the illness experience. By using David Morris's ideas of a new patient-family relationship, and Roland Barthes' reflections on living together and living alone in *Comment vivre ensemble* (1977), I will discuss different manners of living together in times of illness.

## Living with illness

In 1977 Roland Barthes gave a series of lectures at the Collège de France, later published as *Comment vivre ensemble*, in which he introduced the word *idiorrhythmia*. The concept describes the processes by which certain monks on Mount Athos in Greece mediate between an idiosyncratic, personal rhythm and the rhythm of the larger monastic communities. Barthes reinvented the religious concept of *idiorrhythmia* on observing a young mother and her little son:

*"From my window (December 1, 1976), I see a mother pushing an empty stroller, holding her child by the hand. She walks at her own pace, imperturbably; the child, meanwhile, is being pulled, dragged along, is forced to keep running, like an animal, or one of Sade's victims being whipped. She walks at her own pace, unaware of the fact that her son's rhythm is different."* (Barthes, 2012:9)

The concept is used to shed light on individual life lived in a variety of collective situations placed in different settings. The settings were taken from different novels, such as the island in Defoe's *Robinson Crusoe* (1718), the private prison cell in André Gide's *La Séquestrée De Poitiers* (1930) and the sanatorium in Thomas Mann's *The Magic Mountain* (1924).

In reading *The Magic Mountain*, Barthes notes how the rhythm of the sanatorium differs from that of the outside world: *"Once the structure (the Living-Together)*

is established, it's everlasting; it runs on and on – like a homeostat. [...] For the visitor: repulsion and attraction" (Barthes, 2012:37). This contrasting set of feelings may be detected in some of the characteristics of the sanatorium itself. The place is a mixture of seclusion and social life, of living together and living alone in the presence of death. Barthes primarily discusses the sanatorium in *The Magic Mountain* as a place of "very strong investment in human relationships and yet all in a context, against a background, of illness and death" (Knight, 2008:51). He particularly writes about the sanatorium in connection with the figure of 'Cause', but he also reflects upon it with regard to the figure of 'Autarky': "What is the fascination of the small group, the gang of the sanatorium? Well, I think it's precisely the state of autarky: see the Greek term *autarkeia*: self-sufficiency, contentedness, plenitude" (Barthes 2012:36). The patients at the sanatorium are living in a secluded yet self-sufficient world, feeling safe in the repetitive rhythm of daily life – a rhythm that is individual yet somehow also corresponds to the rhythm of the sanatorium as a collective.

The idea of the sanatorium as an extremely intense social setting was not new to Barthes. It was launched in 1947 in the essay *Sketch of a Sanatorium Society*, in which he states: "The malaise of not being social is exhausted through social exercises recreated in the image of those from which one has just been excluded" (Barthes, 2018:64). Interestingly for our discussion, Barthes compares the sanatorium to a family: "Sanatoriums can be great families, no doubt about it. But if one is obliged to spend time there, must he be complicit in such a cheerful familiarization with disease?" (Barthes, 2018:67). Whereas Barthes initially stresses the social aspect of sanatorium life, he then modifies and nuances this by including the figure of Clôture in *Comment vivre ensemble*. The word clôture means enclosure, a limited space: "Enclosure=defines a territory, and by extension the identity of its occupants" (Barthes, 2012:58). At the sanatorium, the patients adjust to one another by means of the strict routines at the institution but are at the same time able to realize their own solemn pace. In Barthes' own ending in the *Comment vivre ensemble* seminar, namely the lecture based on Xéniteia, he includes the Compline, the last service of the day in the monastery, as an ideal place of living together:

*"The idea of compline: beautiful. The community prepares to brave the night (imagine a countryside far away from anywhere, with no lights, so where night-fall really means the threat of darkness). Living-Together: perhaps simply a way of confronting the sadness of the night together. Being among strangers is inevitable, necessary even, except when night falls."* (Barthes, 2012:129)

Barthes' formulation is intriguing seen from the perspective of living with severe illness. Facing death, like all the protagonists in our four novels, is facing darkness, feeling that night is falling. Being together in this hour of the day or in this period of life, as in severe illness brings forth the need of both living together and living alone. Turning to *The Magic Mountain* as Barthes does, Diane Knight in a dense and thought-provoking article explores the relationship between Autarky and Clôture as it is dwelled upon in *Comment vivre ensemble, Esquisse d'une société sanatoriale*, as well as in Barthes's more biographical writings. Here Barthes introduces the regular and obligatory resting on the balcony of the sanatorium as a way of practising the Compline. The Compline and the balcony resting show the combination of autarky and enclosure within the self-sufficient institution scenery: "The balcony is an extension – at once metonym and metaphor – of the solitary chamber in which Hans will spend seven years of his life" (Knight, 2008:58). To have access to such a dwelling place as a sanatorium balcony, being wrapped up in blankets as a sign of autonomy, borders and yet freedom and at the same time belonging to the sanatorium with its family-like organization is suggested as the perfect idiorhythmic way of living.

Barthes' style has been called "eccentric and obscure" and though he is much read, his methodology is not always easily applicable. The concept of idiorrhymia, however, has grown popular due to its resilience and the diverse well-known novels Barthes alludes to: "Barthes's eclectic choice of primary texts [...] offers a model for how researchers might explore idiorrhymia through the work of other creative writers and literary authors, and across a range of genres and media" (Harrow, 2015:21). Not surprisingly, then, idiorrhymia is applied in a variety of fields; such as literary theory, biographical letter writing, pedagogy and philosophy (Knight, 2008; Harrow, 2015; O'Meara, 2012; Stan, 2014).<sup>3</sup> I will transport the concept into yet another discipline, namely medical humanities, using it as a means to reflect upon being a patient in one's family home, living together and/or living alone in the presence of severe illness.

## Young adults living at home

In *Ida's Dance*, Ida is still breaking away from her parents when, as an 18-year-old, she is diagnosed with leukaemia. She still lives at home but, via her somewhat older boyfriend, Jonas, and busy social life, she has begun to find her bearings away from home and her parents. Yet the disease draws her back to her family. In

particular, her relationship to her mother, the narrator, Gunnhild, is portrayed as extremely close, almost symbiotic, and the bond between the two grows throughout the period of illness. The rest of the family also emerge as very intimate carers. Ida and her disease become a family matter as they exchange different tasks in relation to her: mother drops her off and picks her up, big sister prepares meals, big brother brings high spirits, a little new-born niece provides a will to live on, and father contributes towards the family's strong finances. *Ida's Dance* paints a picture of a family idyll and, within a socioeconomically resourceful context, Ida's illness is treated in an exemplary way. One challenge, however, is how to combine the ill person's need for private life with her family's desire to help and support her. In *Ida's Dance*, Ida's position on the bridge between childhood and adulthood is portrayed as demanding for her mother in relation to Ida's romance with her boyfriend Jonas. The mother's challenges in letting Ida be independent and live a normal life are a factor that in-depth interviews with young cancer sufferers also reveal:

*"This tension between parents 'letting go' and young people feeling 'overprotected' was apparent in many of the responses from both studies and serves to illustrate one of the triggers that resulted in challenging family dynamics and which served to exacerbate an already difficult set of circumstances."* (Grinyer, 2009:207)

Gunnhild dislikes Jonas, both because he is older than Ida and because he is accelerating her approach to adulthood. He is referred to as a "scumbag", an extremely negative description given the book's otherwise subdued style and register. The mother provides a candid account of how difficult she finds it to relate to Ida's sex life, and she gives an equally honest portrayal of her jealousy towards Jonas. Ida, however, insists on being with Jonas and her mother grants her wish, eventually accepting the fact that the two young adults will be spending time together. In a scene near the end of the book when Ida is very ill, her mother describes driving Ida to Jonas' flat so that she can spend the night with him. The scene illustrates how the mother recognizes that Ida is not only a child with a need for familial care but also a grown adult with a need for intimacy that her family cannot provide. The novel describes how Ida's need for belonging to the family and claiming her own individuality is taken care of. At the end of her life the family rearranges the furniture so that Ida can rest in the living room in the daytime. However, Ida dies in her own bedroom, in her own bed, tucked up in blankets, with her nearest and

dearest around her. The scene has a subtle resemblance to the balcony setting in *The Magic Mountain*, indicating both a belonging to the group and a place of one's own. Both the mother and the other family members can be said to adjust to Ida's pace, corresponding to the needs of their very ill daughter and sister. Keeping in mind Barthes' reference to the Compline, the monastery bedtime or after-supper prayer, where the monks gather after a day in solitude, Ida's death is rendered as the final coming together before night falls.

In *Let me sleep until this is just a dream* we encounter Mia Jonson, 26 years old, a student of literary science who discovers a large tumour in her cervix at a routine check-up with her gynaecologist. As she is single, Mia's closest caregivers are her parents. Throughout her illness, Mia is transported back to the role of a child as she needs help and care: *"They're in the flat all the time. They get up when I get up, sit down when I sit down, holding out their hands as I cross the floor as if they are standing beneath a nest when an egg is falling. They don't understand what is going on"* (Stifoss-Hanssen, 2014:115). Her parents' desire to provide emotional and practical support illustrates a need recognized in sociological research (Benkel and Molander, 2017:2). Mia's relationship to her parents' caregiving role is ambivalent. On the one hand, she fears being alone and her parents' presence distracts her in a positive way: *"When I'm alone I can feel something spreading within me, grabbing hold of the lymph nodes and squeezing hard. When Mum and Dad are here, I'm just tired"* (Stifoss-Hanssen, 2014:119, 120). On the other hand, she worries about her parents' reaction to the illness and she is sensitive to any sign that it is also difficult for them. In contrast to the caregiving roles in *Ida's Dance*, which appear much better defined because Ida is so young, Mia finds herself at the cut-off point where it is not as natural for her parents to be her most intimate relations. Many 26-year-olds would have a partner; some would also have children.

The fact that her parents only have a substitute role as caregivers becomes defined when Mia realizes clearly that her former girlfriend Anne-Marie should be the one performing the role. The qualities of this secondary role do not naturally fit in with the role of a romantic partner. Mia's previous girlfriend, Kristin, did not fulfil such a role; on the contrary, she is instead compared to the cancerous tumour itself: *"It was her the gynaecologist had seen in there, her forehead and a single eye. She had taken hold, grown over the canal like a deformed head"* (Stifoss-Hanssen, 2014:136). The most effective care is actually her father's; Anne-Marie's attempts of comfort and care and enhanced communication are thought of in a similar way to those of the neighbouring homosexual couple Rolf and Aksel. Their common feature is, that they afford Mia the opportunity to find time to formulate her own



thoughts, as well as to employ humour in an attempt to normalize the situation. Rolf, a practitioner of alternative medicine, gets Mia to open up about how she is feeling. He also puts into words something that is completely central to the novel: “‘It wouldn’t hurt to talk a bit more,’ he said without smiling” (Stifoss-Hanssen, 2014:147). Communication is key in *Let me sleep until this is just a dream*, in terms of love, the work of a writer, and disease. The illness unleashes Mia’s communicative potential. Her writer’s block deserts her and she manages to elucidate her relationship to both Kristin and Anne-Marie. The novel’s coming into being can easily be interpreted as a meta-comment on this (Synnes and Bondevik, 2018:171). This novel is, however, still by far the most upsetting one because the lack of idiorrhhythmia between Mia and her caregivers due to the illness experience only seems to be an intensification of a more general idiorrhhythmia characterizing Mia’s life as an adult. The non-rhythmic pattern of Mia’s life before she got cancer continues when she becomes ill and makes her particularly vulnerable.

## Adults living alone and together

Living with illness can also mean living alone. The main character in Lars Gustafsson’s novel *The Death of a Beekeeper* (1978), the 40-year-old teacher and early retiree Lars Lennart Westin, lives a voluntarily isolated existence following a divorce some years previously. He recounts how his children visit him in the summer holidays, but, as the disease worsens, he withdraws more and more from social settings. The portrayal recalls a biological observation from nature, where it is said that bees withdraw from the pack in order to perish alone. Lars does not withdraw from people when he falls ill, but in light of the illness, he intensifies his isolated existence. His withdrawal from society peaks as he burns the letter from the hospital telling him whether he is ill or not, thereby cutting off all communication with the medical staff.

The burning of the letter from his doctor, in which his diagnosis is presumably stated, is perhaps the most crucial scene of the novel. His desire to remain ignorant is a part of what David Morris calls “[a]n erotics of not-knowing” (Morris, 2017:96). The entire development of Western medicine is based on the acquisition of new knowledge and an attitude like that of Lars Lennart Westin appears counterproductive. The novel introduces alternative ways of confronting disease. It begins with a description of his dog not wanting to follow him and Westin suspects that it does not recognize his smell. He, therefore, suspects that his smell has changed



because of the disease (Regenbogen et al., 2017). However, a conscious neglect is also an option in facing illness:

*"Not knowing in medicine and in illness is, of course, never a steady state. It exists, as if in counterpoint, only in relation to the knowledge that it interrupts, as knowing and not-knowing alternate, collaborate, interpenetrate, or overlap in what is always an improvisation."* (Morris, 2017:96)

If knowledge may slow down or get rid of the disease, it seems obvious that it ought to be acquired. However, if the condition is chronic or terminal it is not necessarily the case that knowledge will improve either life quality or the physiological condition. The desire not to know cannot only be said to be erotic in the word's original meaning; it is also exotic: it is an act that seems strange to the modern disease mentality of Anglo-American and West European cultures. By burning the letter, the protagonist in Gustafsson's novel prevents the medical gaze from entering his life, or to use Barthes' concept, prevents the experience of possible idiorrhhythmia. As the letter is burnt, and he reduces his visits to the doctor to a minimum, the exploration of this challenging adjustment to different rhythms is fully realized.

Physical suffering and pain is an important theme in *The Death of a Beekeeper*. Even when Lars eventually begins to experience strong pains, he chooses not to seek help. Pain has several functions in his narrative: *"It is through pain he experiences that he is a body, amongst other things"* (Haugen, 2002). Lars experiences his body as from a distance making it stand out as an object of its own, which is a common way of responding to disease in the illness literature.<sup>4</sup> The bodily pain asks for a response from him and forces him to communicate and thereby offers a kind of bodily companionship. Pain is, therefore, not only described as negative. Eroticism and pain are linked in *The Death of a Beekeeper*, and orgasm is portrayed in a way that recalls the descriptions of pain: *"incandescent, intense"* (Gustafsson, 1978:149). He writes about *"[...] the troublesome similarity between pain and desire"* (ibid.) and takes note of the erotic excitement that returns when, for a while, the pain subsides. The description of pain as bodily awakening is crucial because it signals harmony and rhythmicity within the protagonist himself. The inclusion portrayed in the novel is somehow balanced by the complex yet balanced feelings, both emotional and physical, of the person. Though he is actually living alone, his heightened and intensified bodily experience, in both pain and lust, provides a feeling of togetherness and completion of himself as a subject.

Ragnar Hovland's *A Winter's Journey* consists of two narratives, namely a diary novel and a fictional narrative, both written by a first-person narrator with limited access to the thought and feelings of the other characters.<sup>5</sup> The main character in the diary narrative is an author and amateur musician recently diagnosed with bowel cancer. He lives a busy social life and has been in a close relationship with his live-in partner, T., for many years. The narrator writes about his and T.'s free lives as artists, filled with travel, music, films, talks and visits to restaurants. The encounter with the health services, with their forms, fixed appointments, reports, technical language and an expedient, professional approach to patients, represents the opposite of their lives as artists.

The diary novel in *A Winter's Journey* runs from 29 April, the day after the narrator is told that he has a tumour, to 31 December of the same year, after he has been operated upon and is declared healthy again. The narrator's plan is to carry on living as before, or, as he writes in the first diary entry: "*I'm going to try to live as normally as possible. Do nice things. Listen to good music and watch great films. Move. Eat delicious food*" (Hovland, 2001:9). This recalls Arthur Frank's fourth category of sickness plots, namely, "illness as normality" in which the patient is to live, to greatest degree possible, mentally unaffected by the disease (Frank, 2010). The partner, T., is completely central to the author's existence, both in illness and in health. T. is the first to be told of the cancer diagnosis and they "*agree to keep the good times rolling*" (Hovland, 2001:9). When the narrator worries about the serious side effects of the treatment he is about to receive, he breaks down before he calls T., who is travelling: "I've spoken to T., and it's something of a comfort to speak to her. She is a blessing. She told me about someone who has lived like this for years, who does mountain climbing and all sorts of sporty activities" (Hovland, 2001:40). T. responds to the protagonist's news in the best possible way, comforting him and giving him hope. She adjusts to his life as a patient by doing what he wants, namely to act normally.

In the fictional part of the book, the main character is Lindemann, an itinerant preacher who has lost his faith. He hitches a ride with a childhood friend, and with a neighbour, Liv, they drive off to find his childhood sweetheart, Johanna. Synnes and Bondevik have read the fictional part as "[...] *a mythologizing of the affliction of cancer and the situation of the diary writer*" (Synnes and Bondevik, 2018:169). I would argue, that the fictional part can be read as an intensification of the diary part's accentuation of a positive social context in dealing with illness. Gaute Sortland makes a similar point, when he refers to the significance of music to both the diary's 'I' and to Lindemann as having a vital social function (Sortland, 2007:47).

Lindemann's trip is motivated by his desire to meet his childhood sweetheart again. The meeting with her does not turn out as he imagined it would, but on his way he is introduced to a number of social relationships that seem to be positive, meaningful and straightforward, representing something important missing in his life so far. Lindemann's poor health and loneliness is compensated for by these meetings, and reflects the "I" in the desire in the diary part to live normally and in close social interaction in the midst of a difficult stage in life. In this way, the importance of living together in the shadow of illness is accentuated.

## Final remarks

Living with illness can both mean living alone or living together. As Barthes so poignantly has shown, life in a sanatorium means not only being part of a tight, yet broad and homogenous society, but also being in a state of loneliness, if not actually alone. The same could be said about being ill at home. The majority of patients today are not alone but surrounded by family or friends. Today, caregiving relatives put in as many hours of work as health workers (Holmøy et al., 2014). Developmental trends point towards increasing use of private health care and a broader use of the family (Jenhaug, 2018:45). The American author and literature professor David Morris has with his book *Eros and Illness* (2017) contributed an important humanistic angle to the role of the relative, by showing how relatives are not only present as a vital aspect of the private experience of illness but also how what he calls *eros* enters the institutional aspect of being ill. *Eros* implies not merely the erotic, but everything that lies beyond reason and is thus diametrically opposed to medicine. Medicine is *logos*, but within it, *eros* is also to be found: "*Desire, legitimized as medical eros, offers a power that can help make the passage through illness far less onerous, a power that offers a more truly 'personalized' medicine than genetic profiles alone can promise*" (Morris, 2017:17).

Medical *eros* is present in all four books discussed here. It is most basically manifested as the undisputed love from partners and parents. But also the representation of pain and *eros* in *Death of a Beekeeper* brings forth a bodily sensation, giving the cancer-stricken protagonist a feeling of belonging that illustrates medical *eros*. *Death of a Beekeeper* is fascinating in its insistence on solitude. Lars is portrayed as living in a monastery, due to his routines, his restricted daily life and his asexual behaviour. He refuses to adjust to the rhythm of the medical community or to family and friends. Instead, he experiences his sick body in an inten-

sely, distanced manner and when experiencing pain or achieving orgasm he feels the idiorrhymia of both living together and alone. In facing illness and pain he meets his Compline. In Hovland's *A Winter's Journey* this combination is realized literally, since the relationship of the patient-narrator and his female partner is characterized by flexibility, intimacy and freedom. They travel explicitly together, and alone, and the daily life of the protagonist is coloured by both the presence and distance of his beloved partner 'T'. They adjust to each other in a seamless manner and represent a good example of Barthes' preferred combination of living together and living alone.

A 2017 study raises the point that "[f]urther research is required on this rarely investigated subject of having an adult child with a severe disease" (Benkel and Molander, 2017:1). The study of biographical and fictional texts such as *Ida's Dance* and *Let me sleep until this is just a dream* is one way of investigating this aspect. The harmony of *Ida's Dance* can be seen because the narrator-mother and the rest of Ida's family adjust neatly to the rhythm of the incurably ill Ida. Ida is the youngest sibling in the family, she is still living at home when she falls ill and the manner her family adjusts to her may be quite similar to how she was treated before her illness. The story of Mia in *Let me sleep until this is just a dream* is the most disintegrated one. Mia and her parents do not follow the same pace and Mia feels alienated both when her parents move into her flat as well as when she returns to her childhood home. Both Ida and Mia have their parents as their most intimate caregivers; yet having access to their capability to perform the role of carer remains a privileged position. It prevents loneliness and counteracts the practical challenges of suffering alone. Corwin's and Stifoss-Hanssen's texts are thought-provoking because they point towards a reversal of the development process involved in being ill and let parents step into the role of caregiver. They demonstrate how *eros* is present, understood both as erotic and as care and support. Medical *eros* is a necessary part of being ill, whether in contact with health personnel, parents, children, spouse, friends or neighbours. In other cases, as we have seen, a decision against a social dimension leads to an intensification of one's own physical presence.

The reading of texts that discuss the role of care recipient both with and without parents being actively involved demonstrates the need for flexibility in health care. This also includes a reminder of the historical changes that have taken place. Roland Barthes wrote in 1947 from his own experience of being a sanatorium patient about the sole benefits of being transported back to childhood:

*"Paternalist, feudal, or liberal, bourgeois sanatorium society, through various pretences, always tends to revert to the irresponsibility of childhood. It is an essentially puerile society, corresponding in its various facets to the bourgeois image of childhood. We know that for most French writers over the last century nothing is as perfect, nothing is as happy, as childhood and there is no human mission more vital than recovering it." (Barthes, 2018:67)*

However, the study of our four contemporary texts on being ill reveals that childhood is not necessarily the preferred setting. For Mia it is highly problematic, and none of the adults in Gustafsson and Hovland's novels indicate any longing to revert to childhood. Rather, they seem to find strength and appreciation in their in-dependency and control over the illness experience. Ida in *Ida's Dance* is the youngest patient, almost a child, and seemingly content. Yet the story narrated by her mother leaves some uncertainty as to what Ida as a patient really means. It is only direct speech from Ida that is rendered. All in all, an awareness of the need for a flexible and subjective approach towards the social setting of being a patient is one general, yet crucial, lesson learned from reading these illness stories.

The four books show that despite the love surrounding the patients, the pace and rhythm of the lives of the ill people and the healthy people are different. Susan Sontag, who was a friend and admirer of Roland Barthes, is known for her opening paragraph in *Illness as Metaphor*:

*"Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place."*

Beginning a book as Sontag does, advocating the need for a concrete, medical language of illness and illness experience by using metaphors, naturally stresses the importance of the statement. The rhythm of these two kingdoms is unlikely to be identical. The rhythms, to use Barthes' vocabulary, can be related or they may differ as illness interferes with daily life. The roles of the patient and the relatives are influenced by the diminished state of health, which is reflected in the idiorhythmia of the stories being told. The question, then, is more one of whether the ill and the healthy people are able to adjust to one another.

Finally, Roland Barthes discusses idiorhythmia in connection with illness, describing the exemplary setting of the sanatorium. The reference to the sanatorium

where the patients both follow the daily rituals of the institution and their own individual pace brings together the living together and the living alone. Whereas fulfilling this idiorrhythmic ideal may be challenging no matter what life situation one is in, experiencing illness clearly places the patient and his or her family in a particularly demanding and vulnerable situation. Family and friends have a great burden of responsibility to adjust to the pace of the ill people. Yet, as shown by both Barthes and *Ida's Dance*, tucking someone in, giving them a room of their own and yet offering company and comfort is one possible and achievable way of practising the difficult exercise of both living together and living alone in the presence of severe illness.

## Notes

- 1 The works by Hovland, Corwin and Stifoss-Hanssen are based on personal experiences of sickness, although only Corwin's is purely biographical. In terms of genre, the books by Gustafsson, Hovland and Stifoss-Hanssen are classed as novels.
- 2 In *Living Conditions Survey on Health 2015*, Statistics Norway uses the following age groups: 16–24 years, 25–44 years, 45–66 years, and 67 years and above. My source material represents the first three groups. Young adults are defined as people aged 18–29 (Bleyer et al, 2017:569).
- 3 For a full exploration of the inter-disciplinary potential of idiorrhythmia, see Stene-Johansen, K., Refsum, C., & Schimanski, J. *Living Together - Roland Barthes, the Individual and the Community* (2018).
- 4 See for instance Agneta Klingspor's *Stängt pga hälsosjel* [Closed due to health concerns] (2010), an autobiographical narrative (pathography) on breast cancer. The narrator treats the cancerous breast as both a part of herself and as an object in itself. Many thanks to Katarina Bernhardsson for making me aware of this expression of bodily dualism.
- 5 The two parts are marked differently. The titles of the diary novel's short chapters are in the form of dates of events (e.g. "9.5") with the text in italics, while the fictional chapters are numbered and the text not italicized.

## References

- Benkel, I., & Molander, U. (2017). A qualitative study of the experiences of parents with an adult child who has a severe disease. *INQUIRY: The Journal of Health Care Organization, Provision, and Financing*, 54, 1–6. <https://doi.org/10.1177/0046958017727107>
- Barthes, R. (2012). *How to live together: Novelistic simulations of some everyday spaces*. (K. Briggs, Trans.). New York, NY: Columbia University Press.
- Barthes, R., & Gladding, J. (2018). *Album. Unpublished correspondence and texts*. New York, NY: Columbia University Press. <https://doi.org/10.7312/bart17986>

- Bleyer, A. et al. (2017). *Cancer in adolescents and young adults* (2nd ed.). Cham, Switzerland: Springer. <https://doi.org/10.1007/978-3-319-33679-4>
- Bondevik, H., & Stene-Johansen, K. (2011). *Sykdom som litteratur. 13 utvalgte diagnoser*. Oslo: Unipub.
- Corwin, G. (2006). *Idas dans*. Oslo: Bokklubben.
- Frank, A. (2010). *Letting stories breathe. A socio-narratology*. Chicago, Ill: University of Chicago Press. <https://doi.org/10.7208/chicago/9780226260143.001.0001>
- Grinyer, A. (2007). *Young people living with cancer. Implications for policy and practice*. Maidenhead, UK: McGraw-Hill/Open University Press.
- Gustafsson, L., & Qvale, P. (1978). *En birøkters død*. Roman. Oslo: Gyldendal.
- Harrow, S. (2015). Living alone together: Barthes, Zola, and the work of letters. *L'Esprit Créateur*, 55(4), 21-38. <https://doi.org/10.1353/esp.2015.0054>
- Haugen, I. G. (2002). *Som om en flytande metall eller något sådant hade trasslat in sig i muskula- turen. Smerte som litterær utfordring i Lars Gustafssons En biodlares død* (MA thesis). Uni- versity of Oslo.
- Holmøy, E. Kjelvik, J., & Strøm, B. (2014). Behovet for arbeidskraft i helse- og omsorgssek- toren fremover. *Rapport nr. 14*. Oslo: Statistics Norway.
- Hovland, R. (2001). *Ei vinterreise*. Roman. Oslo: Samlaget.
- Jenhaug, L. M. (2018). Myndighetenes forventninger til pårørende som samprodusenter i omsorgstjenester. *Tidsskrift for velferdsforskning [electronic resource]*, 21(1), 39-58. <https://doi.org/10.18261/issn.2464-3076-2018-01-03>
- Knight, D. (2008). 'Except when night falls': Together and alone in Barthes's *Comment vivre ensemble*. *Paragraph*, 31(1), 50-60. <https://doi.org/10.3366/E0264833408000060>
- Moseng, O. G. (2003). *Ansaret for undersåttenes helse 1603-1850*. Oslo: Universitetsforlaget.
- Morris, D. B. (2017). *Eros and Illness*. Cambridge, MA: Harvard University Press. <https://doi.org/10.4159/9780674977914>
- O'Meara, L., (2012). *Roland Barthes at the Collège de France*, Liverpool, UK: Liverpool Univer- sity Press.
- Regenbogen, C., Axelsson, J., Lasselin, J., Porada, D., et al. (2017). Multisensory detection of sickness. *Chemical Senses*, 42(2), E47-E48.
- Sortland, G. M. (2007). »Det er ting eg vil vise deg. Fine ting« : melankoli og trøyst i Ragnar Hov- lands roman *Ei vinterreise* (MA thesis). University of Oslo.
- Sovik, O. (2001). Sykdomsbegrepet i historisk og dagsaktuell sammenheng. *Tidsskrift for Den norske legeforening*, 121(22), 2624-2627.
- Stan, C., (2014). A sociality of distances: Roland Barthes and Iris Murdoch on how to live with others. *Modern Language Notes*, 129(5), 1170-1198. <https://doi.org/10.1353/mln.2014.0099>
- Stene-Johansen, K. (2013). Legers plikt til å lyve. *Tidsskrift for Den norske legeforening*, 133(23-24), 2580. <https://doi.org/10.4045/tidsskr.13.1468>
- Stene-Johansen, K., Refsum, C. & Schimanski, J. (Eds.). (2016). *Å leve sammen: Roland Bar- thes, individet og fellesskapet*, Oslo: Scandinavian Academic Press.
- Stene-Johansen, K., Refsum, C., & Schimanski, J. (Eds.). (2018). *Living Together - Roland Bar- thes, the Individual and the Community*. Bielefeld, Germany: Transcript Verlag. <https://doi.org/10.14361/9783839444313>
- Stifoss-Hanssen, E. (2014). *La meg sove til dette bare er en drøm*. Bergen: Vigmostad & Bjørke.
- Strøm, A. (1968). *Lærebok i sosialmedisin* (3rd ed.). Oslo: Fabritius.



- Synnes, O., & Bondevik, H. (2018). Litterære strategiar og sjølvopplevd kreft. *Norsk litteraturvitenskapelig tidsskrift*, 21(02), 161-182. <https://doi.org/10.18261/issn.1504-288X-2018-02-04>
- Talbot, A-M. (2005). Idiorrhythmic monasticism. In A. P. Kazhdan (Ed.), *The Oxford Dictionary of Byzantium*. Oxford, UK: Oxford University Press. Accessed 13 February 2019 at <http://oxfordindex.oup.com/view/10.1093/acref/9780195046526.013.2427>.
- Wiltshire, J. (2000). Biography, pathography, and the recovery of meaning. *Cambridge Quarterly*, 29(4), 409-422. <https://doi.org/10.1093/camqtly/29.4.409>